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Blood, death, and data

Engaging medical science and technology studies

Klaus Hoeyer

DASTS er en faglig forening for STS i Danmark med det formål at stimulere kvaliteten, bredden og samarbejdet inden for dansk STS-forskning samt at markere dansk STS tydeligere i nationale og internationale sammenhænge.

Blood, death, and data

Engaging medical science and technology studies

Klaus Hoeyer

Engaging medical STS

Over the course of relatively few years, science and technology studies (STS) has become recognized as an internationally significant discipline and is today well known also in Danish academia. The present paper serves to inaugurate a chair in *medical* science and technology studies. What is this? I think of the subfield of medical science and technology studies (mSTS) as the study of how social, political, and cultural practices shape medical research, technological innovation, and clinical routines and how these, in turn, affect society, politics, and culture. In other words, it is about exploring the co-production of science and society in a way that, in effect, dissolves clear distinctions between the social and the technological, between semantics and materiality, between culture and nature (Jasanoff, 1990; Jasanoff, 1995; Jasanoff, 2005). It is the study of medical research and clinical practice from a theoretically informed and analytically engaged perspective.

Below, I wish to give an impression of the type of future I imagine for this chair through a narrative of the past that shaped my path towards it, what we might call prospecting through retrospection. The parts of medical STS in which I am particularly interested relate to the interface between governance, technology, and bodies (Hogle, 1999; Kent, 2012; Lock, 2000), especially what have more broadly been defined as tissue economies (Waldby & Mitchell, 2006). I have chosen three cases from my previous research on tissue exchange to illustrate the type of analytical outlook that I bring to this chair and plan to disseminate through teaching and research.

In cold blood? Governing commercial genetic research biobanks through ethics policies

I began my university career with a study of an ethics policy that was claimed to govern a commercial genetic biobank venture.[1] The biobank consisted of a huge collection of frozen blood and stored patient data. It had not begun as a commercial genetic adventure. On the contrary, it was a publicly funded combined healthcare and nutritional research project through which the majority of the inhabitants of Västerbotten, Sweden had, since 1985, undergone preventive health examinations and screenings at the ages of 40, 50, and 60 and simultaneously donated blood samples alongside their data. With the advent of the industrial biotech boom in the late 1990s, several stakeholders realized that the stored samples, at this point numbering more than 80,000, could be considered a 'gold mine' for commercial genetic research. To facilitate the gain and raise funds for new research agendas, a start-up biotech company called UmanGenomics was established. This happened shortly after a major Icelandic biotech venture had established a similar biobank and received international criticism for 'selling the Icelandic genome', and the Swedish newspaper *Aftonbladet* had just presented biobanks as a concealed exploitation of the Swedish public through a series of articles concerning the 'secret research on your body' (*Aftonbladet*, series running through April 1999). To counter public critique and ensure shareholder value, the company developed an ethics policy. The policy was praised in leading scientific journals such as *Nature* and *Science* (Abott, 1999; Nilsson & Rose, 1999) and presented as solving the ethical problems of commercial genetic research.

The highly praised Swedish 'ethics model' presented as a solution basically revolved around methods for ensuring informed consent from individual donors. This is not as easy as it sounds. Informed consent is documentation that the person participating in research

[1] I was lucky to be under the proficient supervision of Professor Niels Lynöe (Karolinska Institute) and Professor Lene Koch (University of Copenhagen).

is informed about its purpose and implications and has agreed to participate. Biobank samples can be stored long after the person has died, and new technological options might emerge that could not have been anticipated at time of collection. The subsequent biobank debate thus came to revolve around 'What does it take to get informed consent?', 'What to do if the donor dies?', 'Can relatives give surrogate consent?', etc.

As social scientists, we can accept such a problematization and make ourselves useful by figuring out who needs to know what. Or we can postpone the demand for utility and explore instead what happens when people are trying to get the ethics right. Rather than joining the many people suddenly complaining about the previous lack of informed consent, I began wondering: Why did biobanking suddenly become subject to ethical debate? Biobanks have been around for almost a century, and despite *Aftonbladet*'s surprise, they never were secret. They were just never before seen as in need of informed consent. So why did people begin thinking of small tissue samples as 'parts of their bodies' long after leaving the bodies in question? Why does the hair left on the hairdresser's floor not raise the same concern? What types of connections between body, governance, and technology were forming through biobank practices?

One of the most curiosity-provoking events in this setting was the way in which ethics was taking on a new form (cf. (Cooter, 2000; de Vries, Turner, Orfali & Bosk, 2006; Elliott, 2007; Hedgecoe, 2004; Rose, 2007). It was no longer confined to Departments of Philosophy; it had become a parameter of competition among biotech start-up companies. Ethics was not about identifying potential value conflicts or applying ethical principles; it was about signalling 'approval' to the public or what Richard Tutton and I have called a form of Kilroy Ethics, "Ethics was here" (Hoeyer & Tutton, 2005). Simply put, ethics was expected to perform a kind of lubrication function for the scientific endeavour and, indeed, several social scientists have criticized these changes in ethics as serving as a veil for exploitation (Black, 1998; Scheper-Hughes, 2001). However, instead of joining either the praise or the criticism of the ethics policy, I wanted to look at what this form of ethics was doing. What did it *produce*?

I cannot present the full analysis here,[2] but it is worth noting that one of the most observable products was an ever-expanding archive of consent forms, of first one page, then two and three pages, all compiled as documentation of individual approval. What used to be blood samples related primarily to research infrastructures were now enrolled in new forms of legal assemblages: archives of documents were constructed to document legality. As I observed the collection of blood samples and interviewed 57 patients about their participation, however, it was striking that donors did not consult the information provided when deciding to participate and could neither recollect any information nor come up with something that would be relevant to know. In fact, it was not uncommon to see them deliberately avoid information, such as when one man kept saying he wanted to sign without reading it, while the nurse urged him to read it before signing, until the point when he asked: "Are you gonna force me to read it?"[3]

When donors neglected the consent procedure, it was not because they had no concerns. It was just that these concerns revolved around topics that could hardly feature in a consent form. I gathered some of these concerns and worked with colleagues to conduct two questionnaire studies asking donors to rate the importance of being personally informed relative to other concerns articulated in the interviews. This provided the surprising result that less than four percent of the actual donors (of whom only 65% recalled they had donated a sample) stated 'being personally informed' as their main concern. In this way, the anchor point of the ethics policy, of recent

[2] Examples include Hoeyer, 2002; Hoeyer, 2003; Hoeyer, 2005a; Hoeyer, 2005b; Hoeyer, 2006.

[3] Several studies have found similar attitudes to information delivery, see e.g., Bister, Felt, Strassing & Wagner, 2009; Brekke & Sirnes, 2006; Ducournau, 2007; Skolbekken, Ursin, Solberg, Christensen & Ytterhus, 2005; Svendsen & Koch, 2008.

legal tightening, and of the international ethics debate, turned out to be relatively marginal to donor concerns. The ethics policy had in a sense instead deflected public scrutiny from the interests of the main stakeholders and had ironically done so through a procedure said to serve the purpose of 'respecting the participants' autonomy'.

Ethics talk has other political consequences too. The constant reiteration of 'ethics' produces a special set of rules of exchange for bodily products. Ever since my work in Sweden, I have frequently returned to this topic (Hoeyer, 2007; Hoeyer, 2013; Hoeyer, Schicktanz & Deleuran, 2013). The body harbours a special potential for public conflict, and it takes work to turn its parts into mobile boundary objects (Star & Griesemer, 1989) that can cross domains otherwise viewed as incompatible, from the person to the marketplace. In a sense, we might think of practices today known as 'ethics' – this new form of social assemblage (Collier & Ong, 2005) – as the kind of infrastructure that connects the 'bio' and the 'bank' in biobanking. In this line of work, I have been much inspired by Michel Callon's work on marketization and performativity (Callon, 1998; Callon & Muniesa, 2005), and just as I studied the commercialization of blood for genetic research in Sweden, I have – with various colleagues – studied the intricate systems of exchange for stem cells (Hoeyer, Nexoe, Hartlev & Koch, 2009), pieces of bone (Hoeyer, 2009), blood and plasma for the transfusion industry (Sheik, Deleuran, Hoeyer, under review), and tissues and organs (Hoeyer, 2013). In these contexts, calculative devices, archives of consent forms, ethics statements, and policies comprise infrastructures through which body parts acquire the ability to move.

In the coming years, I plan to return to the topic of genetic biobanking, this time from a new angle and in close collaboration with other good colleagues, in particular Aaro Tupasela and colleagues from Law and Science as well as here at the Faculty of Health and Medical Sciences. We will explore the move towards international biobanking and investigate how research infrastructures interact with the hopes and concerns of donors, local collaborators, and international partners in the build-up of a biobank based on sampling from many different countries, including South Africa, Pakistan, and the USA. What type of work do ethics rules perform when coordinating the exchange of samples across national borders?

The new project is also an opportunity to investigate further two themes running through all of the studies I just mentioned: 1) a new position for the body in the health services and 2) reliance on informed consent as a form of delegation of decision-making. I will return later to the delegation of decision-making and concentrate first on the way in which each body entering the health services is potentially both patient and source of desired material (stem cells, gametes, skin, bone, organs, etc.): It is both end and means. The double role of end and means is accentuated in the transition from patient in a neuro-intensive ward to brain-dead organ donor, and I therefore now turn from blood to death. I wish to suggest that the double role of the body as end and means serves as a prism for important imaginaries through which we negotiate themes of enduring importance. By exchanging bits and pieces of human bodies, we also change the ways in which we approach and enact bodies, we transform perceptions of life and death, and we change the way we think about duties and responsibilities in our contemporary social contract.

Death, utility, and authority: organ transplantation and anatomical dissection

It is not uncommon in the literature for the transition from patient to donor to be presented as involving some kind of moral degradation (Gunnarson & Svenaeus, 2012; Scheper-Hughes, 2000; Sharp, 2000). Some scholars even view organ donations as the prime example of political exploitation through the reduction of persons to plain meat. Giorgio Agamben (Agamben, 1995), for example, thinks of organ donors as "an extreme embodiment of *homo sacer*", in the sense that it is an instance of "life that may be killed without the

commission of homicide" (p. 165). He sees support for the brain death criterion and so-called presumed consent as examples of how "in modern democracies it is possible to state in public what the Nazi biopoliticians did not dare to say" (Ibid.).

In some recent work, however, I have come to realize that the presumed ethical dilemma between utility and moral integrity might be undergoing change. In collaboration with Maria Olejaz, I have interviewed 33 members of the Danish public about how they contemplate their own death. Some of these were registered as organ donors, others as non-donors, and others were still in doubt about donation. All of them, however, actively contemplated death and used these thoughts to make sense of their own bodies and what it means to be a person as well as to reflect upon what they owe their family and others. Their contemplations indicate a need to move beyond the utility-dignity dichotomy. Similarly, in Anja Jensen's groundbreaking work among Danish donor families, we see how Agamben's characterization of a moral dilemma between utility and dignity might be under reconfiguration (Jensen, 2011). Jensen describes how, for the relatives, organ donation can involve a gradual conversion of hope, from hope for survival to hope for a successful donation. A donation helps make the tragedy of death meaningful for some survivors: the deceased did not die in vain.

First, it is important to remember that in Denmark organ donation from the deceased takes place only when the person is declared brain dead, which happens in approximately 1 out of every 1000 deaths. It is a very unlikely situation, yet it is this situation that public campaigns encourage every Dane to consider. It is, in fact, an intriguing political example of delegation of decision-making, considering that in 999 cases out of 1000, it will have no relevance, and in the one case of unfortunate relevance, the decision-maker will be dead. However, the political strategy has worked inasmuch as organ donation has become a prominent way for many people to contemplate. More and more people also seem to find appeal in the image of organ donation. According to survey material, 30% supported organ donation in 1995, 78% in 2001, and in 2006 this had increased to 87% (Sundhedsstyrelsens Enhed for Planlægning, 2007). Do the people expressing this support consider organ donation a sacrifice involving a 'necessary' degradation of their dignity?

The citizens we interviewed about their future death articulated quite a different valuation of post-mortem utility. Listen, for example, to this registered organ and dissection donor:[4]

> If you donate your body to science, well, then doctors get wiser, and those who come after you will get even better help. It doesn't cost a penny, and I think it's fantastic that it's a possibility. It's absolutely free, but it provides you with a hell of a good conscience.
>
> (Man, registered as dissection and organ donor)

Rather than talking about a sacrifice, this man seems to construe the donation as a positive option. Similarly, a young woman said:

> Well, of course, if I – let's say that I die at the age of 24 – then, of course, I'd really, *really* hope that I would die in a manner making it possible to help others [brain death]. Compared to… dying just ordinarily and then lying there in the grave putrefying bit by bit.
>
> (Woman, registered as organ donor)

Clearly, this woman does not consider donation to be a sacrifice; rather, the public invitation to register her wishes in case of an untimely death has provided her with hope for an alternative death. The image of the grave as a form of wasteful surrender to the worms reappears again and again in most interviews, often in conjunction with ideas about how to avoid placing a burden on those you leave

[4] The following quotes have been used before in a paper currently under review.

behind. I consciously use the word 'surrender' because another theme running through the interviews is an ambition to maintain control beyond the point of death. Not only should you maintain control, you should also avoid burdening your relatives. One man, who had signed up as both an organ and dissection donor, said:

> I've ensured that expenses can be kept as low as possible and the worries to a minimum. So, most decisions are made in advance.
>
> (Man, organ and dissection donor)

This man takes it upon himself to relieve his relatives of potential worries, and in the process, he makes 'most decisions' and retains control. Another man, registered as an organ donor, had gone quite far in planning his death:

> I've also made my own urn, I've thrown and burned and decorated it. It's standing back home on the shelf. It's my 'deceased estate' [*dødsbo*], it's a reminder of life's perishability, you might say. I feel fine that it's how things are, and the kids know it's there, and we've also chatted about how they could pour me out among the strawberries and then taste the sweet berries and think of their sweet daddy and so on [laughs]. So it's basically under control.
>
> (Man, registered organ donor)

There is a striking contrast between this insistence in the interviews on relieving relatives of work on the one hand and dominant representations of death in earlier generations on the other. In the 18th Century, you could be fined if your household did not send a representative to pay tribute at funerals in the village. If it used to be the living who should honour the dead, it is now possible to turn the vectors of duty around and think of the dead as duly serving the

living. And, importantly, the chance of a useful death can be seen as a desirable option. Not everyone feels like this, but I am pointing to a set of transformations through which death and duty can be rethought. Organ transplantation becomes part of such wider social transformations.

We have also interviewed people who oppose organ donation, and here it has been striking how they seem to feel a need to legitimize their position. One young woman, who had registered a 'no', thus said:

> Basically, I think it's just hyper-selfish [*brandegoistisk*] to say no to organ donation.
>
> (Woman, non-donor)

The topic of organ donation had caused serious discussions in her family, and she took care throughout the interview to explain how she compensated for her registered 'no' by embracing other acts such blood donation, stem cell donation, and other good deeds. In light of how unlikely brain death is, it is remarkable that organ donation has managed to provide a public image through which people rethink what they owe society and one another.[5] Registered donors are not just passive containers of human choice: They prompt work and influence relations.

For some patients, organ transplantation is the best treatment option, and for others, it is the only one available. What I am discussing here, however, are not the pros and cons of organ donation. What I have argued is that this technology delivers more than health outcomes. It depends upon and affects socially engrained values, perceptions of death, and notions of right and duty. Science and technology is co-produced with society.

[5] Similarly, Sebastian Mohr (forthcoming) has documented how sperm donation besides medical impact has social impact by interacting with restructuring of kinship, sexual practices, and perceptions of self and other.

One of the current changes that has struck me in the course of this work is how the perpetual longing for control – which can be found in so many other aspects of social life and performance culture – coexists with fear of responsibility. A tacit assumption in much work on medical decision-making is that people are eager to decide for themselves and that doctors should be pressured to delegate decision-making to patients. However, decisions about organ donation are pushed around, and everybody seems to think that decisions lie better with someone else (see Hoeyer & Jensen, 2013). Furthermore, nobody's authority remains unquestioned. Just as I described how the rise of an informed consent regime in biobanking created a diffused and slightly obscure delegation of decisions in which everybody decided for themselves (though nobody seemed to be aware that they were making 'informed decisions'), we see in organ donation a tendency to regard the donor alone as the legitimate decision-maker (according to the law, relatives are not allowed to overrule a decision registered by the potential donor). This is the case even though the donor is taken to be dead and lacking in decision-making abilities. The urge to locate decisions with the individual (dead) body would probably not arise if not information technologies (IT) were seen as 'tools' for storing such decisions-in-waiting. IT infrastructures in this way interact with wider conceptions of legitimate spaces for action in the health services.

In future work, I wish to further explore what is happening to authority in the contemporary health services. Along with changing perceptions of rights and duties come changing perceptions of the legitimate space for action by public institutions (see also (Langstrup & Sommerlund, 2008). Usage and storage of body parts seem to serve as a kind of biopolitical laboratory in which tissue generates governance as much as it is subject to governance (Gottweis, 2010). The sense of body parts as persons by proxy fuels power negotiations in new ways. Such political developments will lay the foundations for future work in the health services, and we need to understand the mechanisms at play. Furthermore, it is important to realize

that the health services are in no way immune to the types of challenges to authority seen in other social institutions (e.g. Snowden and Wikileaks). Whether or not we like the notion of 'context' (for a discussion of context, see Asdal & Moser, 2012), it is important to remember that hospitals are not static institutions; they are mutable networks subject to multiple forms of influence.

As I now turn from death to data, I also turn from often high-pitched ethical debates to mundane everyday practices rarely seen as demanding this form of attention: quality assurance work. STS has contributed significantly to our understanding of the importance of data infrastructures and micro-practices of data registration, storage, communication, and use (Danholt, Bødker, Hertzum & Simonsen, 2004; Helgesson, 2011; Vikkelsø, 2004; Winthereik, 2004; Winthereik, van der Ploeg & Berg, 2007; Winthereik & Vikkelsø, 2005). This is yet another reason for inviting STS into a medical faculty.

Safety logics: data management in bone banking and beyond

In 2004, the European Union (EU) adopted a framework aimed at enhancing the safety of human tissues and cells (2004/23/EC). The directive covers many different forms of human tissues and cells, but in the following, I will focus on bone. In Denmark, bone is mostly procured from people undergoing hip prosthetic surgery. The metal piece goes in, the bone goes out, and in some 5000 cases every year, it is stored in a freezer until it has been tested and can be used for reconstructive surgery after, for example, cancer. The EU rules introduced more testing and a screening procedure using 46 questions to identify potential risk behaviour. The surgeon who is tasked with procuring the bone has ten minutes for a conversation in which he must explain the operation and the follow-up training schedule as well as receive informed consent for the operation and the bone donation. I immediately wondered how the 46 questions would fit

into a busy day, and as I began interviewing surgeons about the new rules, their responses were unanimous: "It's completely mad," "bureaucracy," "absolutely hysterical," and perhaps more surprisingly: "Of course we don't do it."[6] During observations I realized that, in fact, they did not do it – the doctors filled in the questionnaire, let the patient sign, and then sent the fake data to the quality-responsible individuals at the blood banks, who carefully filled the new audit systems with the fake data to 'document safety'.

To avoid giving the impression that the surgeons were simply lazy or irresponsible, let me take you into the clinical space for a moment. Most patients are elderly and severely affected by pain in the hip region. They are nervous about the coming operation. If the doctor were to ask 46 questions, he would prioritize recipients at the expense of spending time on the concerns of the patient in front of him. The concrete patient would be approached as a means and the needs of the potential recipient would be approached as an end. Furthermore, such questions would be seen as interfering with the trust that the surgeons would be attempting to establish. One surgeon explained:

> "It is hard to hint at those things when you interview patients. It's this feeling you get. Right, if you sit there with grandma, 80 years old, and have to ask if she's been out rolling in the hay and that kind of thing, it's a little hard."

In one case, a doctor decided to prove this point to me. He went through the usual procedures with the picture of the elderly woman's hip in front of him.

> "This is where the problem is, the joint doesn't work, and we take this out. You can't use this. But we can. Is it all right that we keep it?"
>
> He then turned to the questionnaire and said:
> "Here comes the interesting part. So have you had…
> Mad cow disease?
> She shook her head
> "Other mysterious diseases?"
> More shaking
> "Anything exciting – risky sexual relations?"
> This time she exclaimed "No!"
>
> And he continued:
> "Tattooed recently? A genital piercing within the last month?"
>
> By this point, she had stopped answering, and he turned to me and said:
> "Usually I would never do this, but she seemed to be able to handle the joke."

I was not absolutely certain that he was right and felt sorry to be the cause of this 'joke'. Intriguingly, I seemed at the moment to have forgotten that the 'joke' was not a far-fetched transgression of standard norms; the surgeon was basically just following the Danish version of the EU rules.

If we think within the existing policy logic, doctors who do not pose the questions are irresponsible and in need of correction. Note, however, that the questions are designed to limit the risk of HIV transmission. In Denmark, there has never been a documented case of HIV infection from bone transplants, and the few international transmissions are from the period before tests were put in place and were, furthermore, from donors who would not have fallen within

[6] This section draws upon material previously published in Hoeyer, 2010a; Hoeyer, 2010b.

the categories of the 46 questions. HIV transmission in bone transplants is – for all we know – a minor problem from a public health perspective. Nevertheless, it costs approximately 11 million Danish kroner a year to uphold the new safety system for bone banks in Denmark. This is not an enormous amount of money, of course, but it is part of a tacit form of prioritizing that is in need of inspection. The 11 million kroner are spent on faulty data management to minimize risk in an area with no documented transfer, and ironically, it has been introduced simultaneously with a budget reduction from 8 to 6 million Danish kroner for HIV preventive work among known high-risk groups in the Stop AIDS Campaign. Furthermore, the amount might not be all that insignificant when you look at it from an EU perspective. The same directive also applies to all other forms of tissue and cell transfers. In 2009, the Commission thus clarified that, according to the rules, men in long-term relationships with women needed to be tested before their semen could be used in fertility treatment for their partners. Researchers from the European Society for Human Reproduction and Embryology (ESHRE) could then document that out of 79,291 tests performed in over 12,500 patients, not a single case of HIV transmission was reported (Hughes, Grundy, Emerson & Mocanu, 2011). At a European level, the cost of continuous partner testing was estimated to be around €240 million annually.[7]

The rules are not made by stupid or evil people. But they follow a set of policy logics in need of scrutiny. Such scrutiny demands curiosity rather than short-sighted attempts to deliver 'solutions'. We need to keep questioning tacit forms of governance embedded in audit systems, calculative devices, and so-called 'technical' directives otherwise never made subject to debate. At least, we must do so if we wish to promote responsible spending in our health services and if we think that respect for the concerns of clinicians and patients

[7] If tests could be reduced to once a year, it would be possible to save €160 million. In response to the 'new evidence', the EU changed the rules in 2012.

matter even when they are not *as* easily accumulated in spread sheets as the fake and manipulated data that surgeons feed to the bone banks to hold the Directive's demands at bay.

In the years to come, I wish to work more with the interplay between macro-measures of governance and micro-practices in data management. I believe there is a great potential for closer collaboration between STS and the public health field, in particular in relation to issues of data management in epidemiological studies (cf. (Holmberg, Bischof & Bauer, 2013). Epidemiologists are usually dependent on many different groups of people who are expected deliver data in order to make 'populations' calculable. Data practices in the Danish health services are in transition in a variety of ways. There are not only increased expectations regarding the collection of data and specimens; data is also seen as relevant for multiple purposes, ranging from quality controls to economic performance management and health research. It is even seen as a marketable national resource for attracting international capital from the pharmaceutical industry. Indeed, a number of initiatives from a series of ministers over the past few years have promoted our health registers as 'goldmines' and means of boosting innovation and Denmark's Gross Domestic Product (GDP). With the recent passing of the EU Data Protection Reform, it was again emphasized that the reform served a double purpose: to ensure citizen rights and to make data available to industry. The EU estimates the value of already-stored data to be over one trillion euros. When there is agreement concerning multiple purposes for the actors involved, this does of course represent a fantastic opportunity. However, even though we in Denmark have grown accustomed to high levels of support for research, the changing structures of authority that I have hinted at above, along with shifting notions of rights and duty, suggest that we cannot take this support for granted. We cannot assume there is agreement. The friction between all of these objectives will involve a generative potential: It will be a catalyst for change in our social contract (Stark, 2009; Wadmann & Hoeyer, 2014).

Today, entering the health services is also entering the registers, and just as I mentioned the double role of the body as end and means, citizens increasingly play a double role as both patient and research participant; in line with the double role discussed above of end and means.

Outlining an analytical outlook

With the three cases above, I have sought to illustrate three aspects of an analytical orientation that I bring to this chair. This is in no way unique to my research, and these three aspects certainly do not cover everything I find important. Rather, I have chosen to emphasize what I think of as particularly productive at the interface between STS and a medical faculty. The three aspects can be summed up as 1) a theoretical preference for thinking of science and society as coproduced, 2) an empirical ambition to elucidate tacit assumptions and unnoticed material practices. And perhaps slightly more controversially, an ambition relating to the practical level: 3) I abstain from immediate 'problem solving' and focus instead on *caring for curiosity*.

First, working with the notion of *co-production* means seeing the concrete material research infrastructure and the socio-legal and moral engagement as mutually constitutive instead of assuming that ethics, society, and governance come either *before* or *after* science has done its part.

Secondly, focusing on unnoticed material practices implies seeing what a biobank sets in motion, what a register instigates, what data practices involve. Instead of assuming that infrastructures simply serve purposes defined by humans, we need to interrogate exactly those aspects of the daily work that are no longer noticed. Focusing on tacit assumptions means conducting a genuine analysis and not just holding out a microphone to record who says what or how many people respond in one way or another to a questionnaire. Qualitative methods are becoming increasingly popular in the health services, but are unfortunately often practiced by people without adequate analytical training. A good analysis must move beyond what people talk about to identify the position from which they are talking. And an engagement with tacit assumptions and silenced practices involves an important critical potential, however old-fashioned 'critical' may sound (Latour, 2004).

What, then, do I mean by my third point about 'caring for curiosity'? The university is faced with ever more strikingly short-sighted demands of utility. And of course, we need to be useful. It sounds so true that only a fool would disagree. But what does 'useful' really mean? Prevalent discourses of utility typically fail to deliver answers to even the most basic questions: Useful for whom? According to which criteria? And requests for usefulness tend to rest on tacit assumptions about ready-made problems waiting to be solved even though social science research has shown for decades that 'public problems' tend to reflect little more than available solutions and prevalent societal norms and prejudices (Blumer, 1971; Koch & Svendsen, 2005; March & Olsen, 1976; Spector & Kitsuse, 2001). In different time periods, social scientists and medical researchers have been called upon to 'solve', for example, the 'negro problem' or the 'gay problem' and only in hindsight have they realized that such framings said more about those defining 'problems' than those claimed to be problematic. As university researchers, we need to be less myopic when thinking about problems and let our analysis take into account the processes through which problems are defined as well as the consequences generated by prevalent solutions (Ferguson, 1994; Shore & Wright, 1997; Shore & Wright, 2011). Rather than having problem-solving and utility as my primary aim and measure of success, I think of our central task as a matter of caring for curiosity long enough to see things anew and thereby to also acknowledge the hopes and concerns not yet acknowledged in the public calls for utility. I basically wish to make problems *thinkable* anew (cf. Miller & Rose, 2008). Indeed, I think this might be much more *useful* in the long run.

Concluding remarks

This inaugural lecture has outlined a personal engagement with a set of social, political, and technological changes. I have pointed to a radical transformation in the social meaning and function of ethics that interacts with ongoing political reconfigurations of authority and notions of right and duty and rapidly developing research and decision-support infrastructures. I have approached these reconfigurations as they become enacted in negotiations about how to handle the new double role of the patient's body as means and end in the health services. Finally, I have argued that it is important to acknowledge the interdependence of science, technology, and society.

This faculty cannot reach medical goals if it ignores social dynamics, and it needs to acknowledge so-called medical goals as socially engrained values. They serve as visions of a good society and need to be approached as such. Along with new medical technologies, we produce new societies, new senses of obligation, new entitlements. Just as esteemed colleagues at this faculty seek to document health outcomes, we need to document what we might colloquially call social outcomes but which can more accurately be described as new socio-techno-political forms of being in the world. In a sense, this type of work is aimed at socio-technical sustainability. It must build upon genuine curiosity, but it can satisfy much more than curious minds.

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